

NAMI Conference Jun 28 – 1-Jul-2017: personal Notes by J. Nelson

Key points have been incorporated into our 1-Aug-NAMI El Dorado County newsletter which is also posted to our Facebook page. Key points are also incorporated on our namieldoradocounty.org website...and photos uploaded to the PHOTOS section on the lower left of our website.

This was one of the best NAMI Conferences to-date. A great many industry leaders and neuroscientists were on the agenda. Many networking opportunities were also presented to improve local services & supports as well as influence and inspire thinking at the individual and state/national level.

Andrea Peterson, author: On Edge: A Journey Through Panic Attack Anxiety.

Panick attacks...typically hers and most people's lasted 10 min but she had one that was a month long with various peaks and valleys. That is when she was diagnosed in '89 w/Anxiety Disorder.

Avg delay to treatment

- about 10 years: Anxiety disorder
- about 16 years: Social anxiety disorder
- about 9 years: GAD

Anticipation of pain. Cognitive frame of anxious mind “what if, what if, what if” Fight or flight response. About 1 in 3 of us will experience anxiety disorder at some point in our life. It is the most common mental health issue. 17% of college students have anxiety disorder...

Often starts in childhood and is a pre-cursor to other disorders such as substance abuse, depression, and/or suicide.

CBT helped her. Women are twice as likely to have anxiety disorders with the exception of social anxiety disorder which is more common in men.

Those with anxiety may notice violence of threat “intention bias”

Those with anxiety see more peril in the world. SSRI's don't work for 1/3 of people so additional treatment modalities are key:

Attention Bias Treatment modification coupled with CBT works well. Some studies assessing if you can overdose on Attention Bias Treatment from too much attention bias modification!

Having therapy in morning; we have a boost of Cortisol levels then which helps enhance learning. Also a nap after therapy helps consolidate what you have

learned in therapy. Taking exercise to consolidate learning and enhance memory is also useful.

TMS is helpful for anxiety. fMRI neurofeedback
Ketamine “fast action with depression”

There are many new “in pipeline treatments – we will see how it all plays out but good brain research going on!”

Clueing in friends about your anxiety at work/home can be profoundly helpful. They can support your authentic self. It is exhausting to wear a mask.

She made it her motto to tell people by 2nd date that she has panic attacks! 25 years of living with anxiety disorders. For her the optimal treatment is SSRI's + CBT + minimum 8 hours/night sleep + exercise including yoga for mindfulness and focusing on “being present.”

Anxiety is all about the worry about the “future state” so mindfulness is helpful. For her scrubbing toilets or baking brings her a sense of calm.

She is often asked “If you could would you wish it all away?” Her answer is she cannot see it as a gift; nor can she erase her life, love and energy. However it enriches her relationships in that she connects with others in pain. It is a great “b.s. detector” and helps her live a more authentic life and not take things for granted.

She definitely still has periods of depression and reminds us all that anxiety often presents earliest as depression and goes hand-in-hand with depression. It is also a gateway disorder concluding there is great opportunity to stave off early to avoid other disorders in adulthood. For example, BiPolar disorder can initially present as Anxiety Disorder. The severity of the genetic mutation can researchers at Stanford have studied where a person walks for health makes a difference in their anxiety levels. It may sound obvious but we now have clinical and statistical data illustrating that walking next to a busy highway vs walking in a picturesque park filled with nature. This gives credence to a biological neuro-biological factor.

Over 30 pages of references are included in her awesome book.

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Plenary – by Mary Gilberti, NAMI President

NAMI Quilt of Justice. We were over 1000 strong marching on capital hill. Senator Chris Murphy and Senator John Croynyn have brought bipartisan amendments for improved mental health services and supports...

Bexar County Texas video – They...now provide video visitations.

Also Lubbock TX county MH now proactive in working with homeless community to proactively find them, get them services, and into treatment or diversion programs. They are providing flexibility of diverting to AOT program or community services

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Notes on a Banana, by author David L

Notes on a Banana: A Memoir of Food, Love, and Manic Depression
by [David Leite](#) – I just finished reading this book – excellent.

Memoirist, cookbook author, food writer and blog publisher and a frequent guest on “Connecticut Style,” “The Today Show,” “NPR’s Mad Hungry,” “Cooking Today, Splendid Table, and is a judge on the Food Network’s “Beat Bobby Flay.”

Super funny book and fun presentation of his life’s story. He discusses the importance of humor. He is son of immigrants from Portugal. He also acknowledges that he has been “out of the closet” so many times he should have installed a revolving door. His book is entirely about acceptance. His mom left him loving notes on a banana – sort of the snapchat of social media of the 1960’s. You read the note on the banana then it disappears after you peel it, eat it and toss the banana.

Humor creates camaraderie. It helps others. He refers to those that do not have mental illness as “civilians” then adds sarcastically “like there really are any people truly without mental illness.” The audience roars with laughter and a standing applaud.

It is hard to hold someone with mental illness at arms length with the embrace of humor. Humor makes others feel safe to connect, safe to share their story and also hear our story.

David says his Mom left him empowering and inherently funny messages on a banana routinely as a child. He adds “plus they are just inherently a funny fruit!”

Humor can dramatically alter a life in favor of mental health. Humor, laughter, and a “crap-load of Shameless re-runs” and treatment help him maintain wellness.

No One Cares About Crazy People: The Chaos and Heartbreak of Mental Health in America

By Ron Powers

This book is Available at the El Dorado County library. I just finished reading – it is excellent.

He shares openly about his 2 sons both diagnosed with schizophrenia. Kevin took his own life one week before his 21st bday... and the other, Dean is 35 working hard to make a life for himself.

“The secret source of humor is not joy but sorrow” Mark Twain

He references a famous speech by Dorothea Dix in 1843 to the Massachusetts Legislature. Quoting a portion of it:

I come to present the strong claims of suffering humanity. I come to place before the Legislature of Massachusetts the condition of the miserable, the desolate, the outcast. I come as the advocate of helpless, forgotten, insane, and idiotic men and women; of beings sunk to a condition from which the most unconcerned would start with real horror; of beings wretched in our prisons, and more wretched in our almshouses. And I cannot suppose it needful to employ earnest persuasion, or stubborn argument, in order to arrest and fix attention upon a subject only the more strongly pressing in its claims because it is revolting and disgusting in its details.

5 I must confine myself to few examples, but am ready to furnish other and more complete details, if required. If my pictures are displeasing, coarse, and severe, my subjects, it must be recollected, offer no tranquil, refined, or composing features. The condition of human beings, reduced to the extremest states of degradation and misery, cannot be exhibited in softened language, or adorn a polished page.

6 I proceed, gentlemen, briefly to call your attention to the *present* state of insane persons confined within this Commonwealth, in *cages, closets, cellars, stalls, pens!* *Chained, naked, beaten with rods, and lashed into obedience.*

He then adds “**I’m looking at you congress!**” For this our audience gave a thunderous heartfelt applaud. He discusses grotesque treatment of consumers turning so many of the “insane” into “criminally insane.” Ron shares a very real example this past week where Tyler West, age 19 lives with his adoptive parents in Michigan. He is diagnosed with several pervasive disorders since early years including autism, BiPolar to name a few. He was bullied fiercely and repeatedly during his school years. He is a kind, quiet, and gentle 19 year old. He wandered out of his home and into the neighbor’s home and fell asleep on their couch. The neighbors called the police and he was arrested for home invasion. He has now been incarcerated for 5 months at the Muskeegan County jail purely “awaiting trial.” Muskeegan County jail has no mental health provisions.

Beaten in his cell by his fellow inmate while the guard sat back and watched – he has spent 2 weeks without his medication slamming his head against the wall. His parents cite “we live with a hole in our hearts.”

“We must break our silence” says Ron Powers.

Dorothea Dix: If County Jails must be resorted to for security against the dangerous propensities of madmen, let such use of prison-rooms and dungeons be but temporary.

We must break our silence!

Dorothea Dix: Cast from shackles which bound them, this bell shall ring out hope for the mentally ill and victory over mental illness.

<http://www.kokomoherald.com/Content/Community/Community/Article/Ring-the-bell-for-mental-health-awareness/32/759/31207>

The NMHA Bell

During the early days of mental health treatment, asylums often restrained persons with mental illnesses by iron chains and shackles around their ankles and wrists. With better understanding and treatments, this cruel practice eventually stopped. In the early 1950s, the National Mental Health Association (NMHA) issued a call to asylums across the country for their discarded chains and shackles. On April 13, 1953, at the McShane Bell Foundry in Baltimore, MD, NMHA melted down these inhumane bindings and recast them into a sign of hope: the Mental Health Bell. Now the symbol of NMHA, the 300-pound Bell serves as a powerful reminder that the invisible chains of misunderstanding and discrimination continue to bind people with mental illnesses. Today, the Mental Health Bell rings out hope for improving mental health and achieving victory over mental illnesses.

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River of Time: My Descent into Depression and How I Emerged with Hope

By Naomi Judd – excellent read and includes family photos and emphasizes treatment that works – just finished it – loved it.

Naomi Judd wore a hot pink dress and shared her personal story with candor and a few painful tears mixed with some humor. I was seated front row center and felt a deep connection to her personal story.

Naomi won 6 grammy's, traveled the world, graced the cover of the most popular magazines, and led a life of purpose. She has been on Oprah more times than any other guest. She worked as a registered nurse over 8 years before getting into the music business.

Things changed for Naomi when she was diagnosed with Hep-C and given 3 years to live by a doctor that actually yawned when giving her diagnosis.

She is also living with severe treatment resistant depression and Bi-Polar with tortuous and extreme panic attacks. She has felt like she has been in a deep dark bottomless pit with serious desire to jump off a bridge to end her pain.

After the “Judd’s Farewell Tour” she experienced severe panic attacks and found herself organizing and re-organizing her closets and cleaning repeatedly. She shared humorously her fond memories of being in the same Brownie troop as Mariskta Hargatay! So she found peace in watching episode after episode of Law & Order re-runs. Her husband, Larry, noticed a severe change in her behavior and was worried about her. He suggested she see a professional. Ashley (her daughter) lives on the farm next door to her. Ashley called 911 to get her Mom help.

The next thing she knew she was at the Vanderbilt Psychiatric Unit taking Seroquel which paralyzed her body but her mind was fully awake.

She captured the audience sharing her personal traumas. You could hear a pin drop in the room as Naomi in front of over 1000 people shared how she was sexually molested by gross Uncle Charlie around age 3 ½ and forced by her grandma to stand next to him in a photograph. She felt she would never be safe again within her own family unit. And so began her fierce independence.

She challenged each of us to think about our first big trauma in our life. What was the lesson we learned from it? She quotes Socrates “an unexamined life is not a life worth living.”

Naomi graduated in the 1960’s. Her brother died of Hodgkin’s Disease the night before her senior year prom. She was also date-raped right before she started her senior year. When she told her rapist she was pregnant he left town and she never heard from him again (even after fame and fortune.) Wynona Judd was his child and Naomi gave birth to her literally on her high school graduation night!

Her daddy left their family for a young girl and her mom attempted suicide. She shares how every single generation in her family have a death by suicide and additional suicide attempts in her family tree.

She speaks about her life lesson: “there is no such thing as security. Real security comes from within. Being flexible, adaptable, and resilient will take you far.”

At the age of 22 Naomi was beaten and raped by a heroin addict. It was only when he passed out on heroin that she managed to escape.

She feared for her sanity and was fortunate to find top psychiatrists and neuroscientists – many of whom she has long-standing friendships with now. Dr. Gerald Rosenbaum of Massachusetts General in Boston helped her tremendously among others.

The last chapter of her book contains excellent description of genetics and environment. She says she came to fear her genetic predisposition but Dr. Rosenbaum helped her understand that genes can be expressed or repressed based on our environment.

She has now not had a panic attack in over 1 year. Her depression has been lifted for the past 14 months. She provided us a hand-out of her top 10 tips that have helped her.

Dr. A. Eden Evans expert in Smoking Cessation Treatment...

Shares examples of 3 pack a day smoker living with schizophrenia who quits within a week

Smoking has 10-year impact on health. Quitting smoking works. If you quit by age 40 no difference

50 years after 1st surgeon general's report 55% drop in smokers in general US population ??

Smoking prevalence with SMI is 53%. 28 year mortality risk for those living with schizophrenia.

4-6 fold chance of quitting if on Chantix or Bupropion and Nicotine Patch. Reduced stress, anxiety and improved quality of life. Average level of anxiety goes down.

AMA 2014 Koegeler

Varenicline = chantix 2.5 times greater results over Nicotine patch alone
Bupropion = known as Zyban when prescribed for smoking cessation and Wellbutrin when prescribed for depression

Removal of [black box warning on Chantix](#) Dec 2016.

Increase success in quitting 2.5 x greater for general population and 5x (5-fold for those with schizophrenia)

Taking both Chantix, the nicotine patch and receiving CBT is best practice.

CBT only: results in only a 5% chance of quitting

For all addictions one needs extensive long-term treatment. Addiction is not something you just “get over.”

Dr Evan's Dad for example has been using nicotine gum since 1991 when he stopped smoking. **Those with schizophrenia or bi-polar are the fastest population to relapse off treatment on placebo!!** JAMA 2014 – look at 50th anniversary edition where Dr. Evan's name is listed first.

Relapse is normal; expect it; plan for it; achieve success. Average smoker will try quitting 5 times before quitting. Should get counseling for quitting smoking. Chantix is under-prescribed by MD's.

Smoking costs 6 hours of life expectancy each day for those smokers over age 30.

The [EAGLES trial](#) ; FDA designed trial included over 8000 smokers studied ½ with SMI; largest smoking cessation trial study. First ever study of inclusion of nicotine patch for those specifically with schizophrenia. respectively. Varenicline-treated participants achieved higher abstinence rates than those on placebo (odds ratio [OR] 3·61, 95% CI 3·07 to 4·24), nicotine patch (1·68, 1·46 to 1·93), and bupropion (1·75, 1·52 to 2·01). Those on bupropion and nicotine patch achieved higher abstinence rates than those on placebo (OR 2·07 [1·75 to 2·45] and 2·15 [1·82 to 2·54], respectively). Across cohorts, the most frequent adverse events by treatment group were nausea (varenicline, 25% [511 of 2016 participants]), insomnia (bupropion, 12% [245 of 2006 participants]), abnormal dreams (nicotine patch, 12% [251 of 2022 participants]), and headache (placebo, 10% [199 of 2014 participants]). Efficacy treatment comparison did not differ by cohort.

Result: 1 hour of CBT in group setting most affective; coupled with psychopharmacological treatment (Chantix or Zyban) and coupled with for example a 21 mg Nicotine patch and optionally nicotine gum. Nicotine helps improve cognition, memory and attention even in non-smokers! Nicotine improves working memory – this is directly seen in those with schizophrenia for example. Nicotine is a cognitive enhancer that is addictive. In fact nicotine is neck-and-neck with heroin in terms of addiction. . It is all the “other stuff” in cigarettes that is most harmful.

There is no good data that e-Cigarettes help quit smoking and they are filled with very unhealthy chemicals (and outside the FDA pathway.)

Quitting directly helps improve quality of life for those with schizophrenia. Helps with self-control, anxiety and stigma and overall health.

Physical exercise can help decrease cravings. From a cardiovascular perspective losing 100 pounds is equivalent of stopping 1 pack/day of cigarette smoking. Learn more at www.trytostop.org. Keep in mind that evidence-based study demonstrates that best results are long-term (perhaps life-long) use of

psychopharmacology, nicotine patch, and CBT for those with serious mental illness and specifically schizophrenia.

There is a ritual that comes with smoking. It is a huge part of the addiction and habit. This can be addressed with CBT. For example, finding things to hold, or placing a rubber-band around the wrist and snapping in, putting something in your mouth, walking, etc.

Dr. Evans advises to not even think about quitting until you have a planned “quit date.” Quit dates should be 8 weeks out (best practice and codified in FDA prescription guide.) Answer the question “why do I want to quit.” Take a month to practice alternative rituals to quitting (such as rubber-band around the wrist so you can snap it repeatedly in place of smoking, or a specific walk you can do instead of ritual of smoking.)

Innovations in Reducing Incarcerations:

The incarceration of people with mental illness in the U.S. is a national crisis. Each year, approximately 2 million people with serious mental illnesses are admitted to local jails, and more than 400,000 prison inmates are diagnosed with serious mental illness at any point in time. Some states and counties are implementing innovating programs to reduce unnecessary incarceration of people with mental illnesses. Initiative in Colorado working in collaboration with Arlington VA is presented. Use of tablets for family video visits (without internet access purely for commissary ordering and family interaction is provided as some jails.) Using a “formulary exchange model” is reducing the costs of medication and enabling adherence to doctor prescribed medication (instead of often less effective jail formularies designed for cost savings and not optimal health treatment.) *[For example long-lasting injectable medication may be what is prescribed going in but the jail's formulary may be oral form which is metabolized differently and introduces an opportunity to go off medication.]*

Reduce Incarcerations through Adhering to Doctor's Prescribed Formulary and Not Just what is allowed on “jail formulary sheet” designed to save \$ and not focused on mental health parity.

Colorado:

- Jan 2017 introduced to Senate
- May 2017 signed by House
- June 2017 – Governor expressed concern about costs to implement but allowed this to become law without his signature.

Creating health information exchange with deeply discounted prices. For example a traditionally \$80/pil vs \$10/pill through purchasing as a co-op (exchange.) . Working now with county jails (25 out of 57 jails implementing and anticipate 80% on-board and implemented by Sep.)

Arlington, VA collaborated with MH and Criminal Justice. Long history of collaboration. Mental health ride alongs with police. Human beings are suffering not just related to MH calls. **Best Practice: Police captain is assigned in 3-year increments to real-time collaboration with family, county MH, jail, etc. 10 years ago County MH would say “Don’t tell us how to assess and we won’t tell you how to arrest.” Significant progress has been made!**

The Sequential Intercept Model originally developed in 2006 is only successful through collaboration and participation and open dialogue; every county benefits by creating a Sequential Intercept Model committee to look at ways to improve.

Peer specialists should be included (NAMI helped devise a [guidelines](#) for this.)
Sheriff's Deputy – CIT leader
BH leader
Public Defender
Prosecutors
Probation
Judge
State Probation
NAMI

Meets monthly – look at risk factors to avoid re-arrest. Create forensic case management and jail diversion teams, train jailers (correction officers) in CIT with more seasoned officers receiving full 40-hour Memphis-model CIT.

Two Perspectives on Genetics:

Known for a long while Mental Illness highly heritable On average men with schizophrenia have 75% fewer children; same with autism. Women with schizophrenia have 50% fewer children.

Risk statistic matter where understanding genetics. It places a limit on how genetic effect can be on the population. A common genetic difference among people can have an effect...rapidly pushed out to do evolution. Common genetic differences spread across the genome

More than 100 places in the genome risk for schizophrenia. These risk factors act together. This means we all carry a genetic risk for mental illness. Genetic risk factor for MI relate to many other behavioral and developmental traits. The genetic influences on schizophrenia don't "just" relate to schizophrenia. Same with autism. The de novo variants are associated with intellectual disabilities, seizures, epilepsy, motor delays etc.

Polygenic risks

Autism and BP are associated with more education: Genetic risk factors for autism associated with those with higher IQ's!

Those with Bi-Polar in general population are associated with greater creativity and more empathy.

"How can we have such illness that causes such pain and suffering but also associated with such positive common traits creativity and empathy and higher IQ?"

But we tend to think of "traits" differently. Instead of thinking "yes" we are affected or "no" we are unaffected we need to think of traits or tendencies. We think of traits as there is a list of polygenetic influences for autism risk in the general population because these greatly overlap. **Greater polygenetic risks for schizophrenia are associated with greater creativity and empathy** for example.

Some of these differences is the way polygenetics works in the "way" they happen ... must be important to understand what you are treating...good to know suite of outcomes.

Dr. Josh Gordon, joined as Director of [NIMH](#) in September.

UCSF trained (MD and Ph.D.) with extensive experience in brain plasticity and well-known for his work at UCSF in genetic mutations into mice and the impact on brains.

Dr. Gordon is passionate about the relationship of genetics to Neuroscience and the impact to treatment models. "Genetics is a game-changer in the science of psychiatric research. It is a biological tool box of your genomes."

Strong collaboration and friend of NAMI's – canceled his personal vacation to be here (and met with NAMI on day 2 of his job to identify ways to jumpstart drug discovery.

"Only through listening to our patient's stories can we design best treatments."

Early in his career he became optimistic about psychiatric neuroscience. NIMH provides \$ for research for excellent science. Science that is strong in design and diversity (subject matter, workforce, research participants and timeframes.)

"Only through research about the brain will we make HUGE advancements in the lives of those with mental illness."

They have done excellent research on suicide prevention and neuroscience. The budget of the NIMH has increased most these past 2 years after being flat for

many years which is enabling them to think big. 23% of ideas on average funded by NIMH. Congress doesn't just give \$ but sets a formal relationship. NIMH and SAMSHsa to being evidenc based is core. We now have evidence based care for suicide prevention. We have RA1SE – cumulative states with early psychosis intrvention plans.

“Understanding genetic predisposition is key.”

There are key things we know about schizophrenia:

- 1) It is a polygenic disorder (no “one” gene that accounts for this; there are many genes that increase the risk.)
- 2) Something about our “early” environment influences the risk. Take for example identical twins – and yet only 1 twin may get schizophrenia. Scientists are studying “why.”

Genes code for how a cell behaves. They form networks. Neurons for circuits. A circuit is one part of the brain that talks to another circuit which causes our behavior.

To understand behavior of a delusion we must ask “how do we understand it” [22q11 Deletion Syndrome](#). If you have this you have a 30% chance you will experience psychosis and 25-30% chance you will get schizophrenia. However it only accounts for 1% of those that get schizophrenia (1% of 1.1% of the population.)

All of the genes on the chromosome that get deleted they have discovered [Dr. Zakharenko, Nature Medicine](#) 2017 deficits in Thelomo cortical synaptic strength. Increase actividy includes the auditory cortex of individuals with schizophrenia. As you stimulate more (Black line) “ed line weaker in mutant mas; input from the thalamus is weaker. The music trying to heighten to the outside world ...it turns up the volume.

This can be likened to turning up the stereo too much – you get noise you don’t get clear fidelity. This is noise in the auditory cortex.

[Dr. Zakharenko showed miRNA](#) – DRD2 – antipsychotics block D2 receptors but doesn’t work fo all. So, the hypothesis is this pathway is broken. **Thalamic miR-338-3p mediates auditory thalamocortical disruption and its late onset in models of 22q11.2 microdeletion**

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pp39 – full text [here](#)

Refer to the [ED-SAFE study](#):

Most of those that die by suicide have in fact been to the ER in the past year. Following the evidence-based-model to have someone call the patient 24 hours after release from ER can save lives....and again to follow-up to ensure they get a referral to a specialist. With universal screening detection rate doubles. Missing half of people without doing this. Led to 30% decrease over 1 year following.

Brief Behavioral Therapy for Pediatric Anxiety and Depression in Primary Care:
JAMA

Anxiety in childhood predicts risks for greater mental health issues in adulthood. BBT is what normally helps and is in practice today. Patients stayed in their treatment longer (lasted longer) when done in a primary care setting. Hispanic populations get better effect if the care is delivered in schools. Active participation by supportive family members helps!

Resting state connections: Can get sort of a frequent resting state connectivity compared to others. For example thousands of scans of those with depression. Then assess and cluster them into for example 4 different types of people with depression. But it also tells us clinically what is going on symptom-wise. Cluster 1, cluster 2, cluster 3, cluster 4. We are a few years away but making huge progress.

Repetitive transcranial magnetic stimulation actively be investigated and turns out 18 in subtype 1 you respond more to TMS. In order to be useful clinically they need to know what are best treatments by sub-type! So they can tell you will have a 70% greater improvement on this treatment model vs that treatment model.

The result is "[The All of Us Program](#)" that will 1,000,000 subjects across the US to test genetic hypothesis. Volunteers will submit behavioral assessments through a portal about their lifestyle to help pave the way towards precision medicine. Deep phenotyping and behavioral testing and surveys on strength using a large-scale data-driven approach with defined "categories" to get better medicines identified by category.

The british are coming! NAMI's next annual conference will be in New Orleans. Dr. Turkington and Kingdon, founders of CBT for treatment-resistant psychosis are coming...so NAMI is arranging half-day or full-day with them.